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ABSTRACT

Procedures for the evaluation of patient education programs have been slow to evolve; the majority of programs, in fact, remain unevaluated. Patient education efforts, particularly with cancer patients, are effective in enhancing recovery, alleviating anxiety, and facilitating compliance. Patient education should minimize patient dependence on others in the recovery process. Its design must insure cost-effectiveness. A conceptual model has been designed for the evaluation of patient education; quasi-experimental design appears to be practical. Educational programs have multiple objectives with immediate and intermediate objectives being most crucial because of time and cost constraints and available techniques. Success is dependent on the criteria employed for evaluation. Patient education best lends itself to these criteria: effort, performance, adequacy, efficiency, and process. A systems design evaluation model helps clarify cause-effect associations and provides accountability with examples of input, intervening, and output variables. (Author/GDC)

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A CONCEPTUAL MODEL FOR EVALUATION OF
PATIENT EDUCATION FOR CANCER

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ABSTRACT By tradition, patient education in the health care system is accepted as being effective in enhancing recovery, alleviating anxiety, and facilitating compliance. Patient education also must be planned to minimize patient dependence on others in the recovery process. Its design must insure valuable cost-effectiveness. However, the health care profession has been slow to evolve or adapt scientific methodology for evaluation of educational processes. Modalities vary, but the majority of patient education programs remain unevaluated. Design of conceptual model for evaluation of patient education requires specific steps in evaluation research. Quasi-experimental design appears most practical for use in the health care environment. Educational programs will have multiple objectives with immediate and intermediate objectives being most crucial because of time and cost constraints and available techniques. Success is dependent on the criteria employed for evaluation. Patient education best lends itself to these criteria: effort, performance, adequacy, efficiency, and process. A systems design model for evaluation of educational strategy to help clarify cause-effect associations and provide accountability with examples of input, intervening and output variables is provided.

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The purpose of this presentation is to provide a conceptual framework for evaluating the effectiveness of patient education within the health care system. Although we have narrowed our attentions to cancer, the framework is applicable to any patient health education endeavors. Individuals who are stricken with disease or symptoms of illness typically enter into the medical care domain to achieve personal goals. However, the patient's thought processes in such situations may be less than rational (being compounded by anxiety and emotional unrest), and he/she is in need of the health professionals' command of esoteric knowledge to alleviate not only the disease processes but also the associated anxieties in order to promote recovery. This is particularly acute when the disease is cancer.

A primary element in this process is the provision of patient education. Thus an essential question must be raised; Are specific educational programs created to inform, motivate, teach, and change patients' attitudes or behavior successful? To answer this question, empirical determination of the benefits of patient education is required.

The specific purposes of this paper are stated as follows:

1. to provide an overview of patient education in the United States

2. to outline the central features of evaluation research
3. to provide a conceptual framework for evaluating the efforts of patient education.

Health Care System and Education

That the health care system is an exceedingly complex educational machine is well documented from ancient times. The Greek word "doctor" of course means teacher and the word doctor in the public's mind still is most frequently applied or associated with the physician. Early development of this role even at the highest level of the state, can be seen in the early writings of Maimonides.¹ Furthermore, contemporary society is investing enormous amounts of money in the educational effort for the health care system which involves all levels of society. A flow diagram of a typical disease control program is shown in figure 1 stressing only a few of the levels at which educational work is performed.² Figure 2 illustrates the place of education within the overall health care system.³ The nature of this education may be public information, patient assistance, or manpower development. Regardless of the type, all need to be evaluated for their impact upon the system.

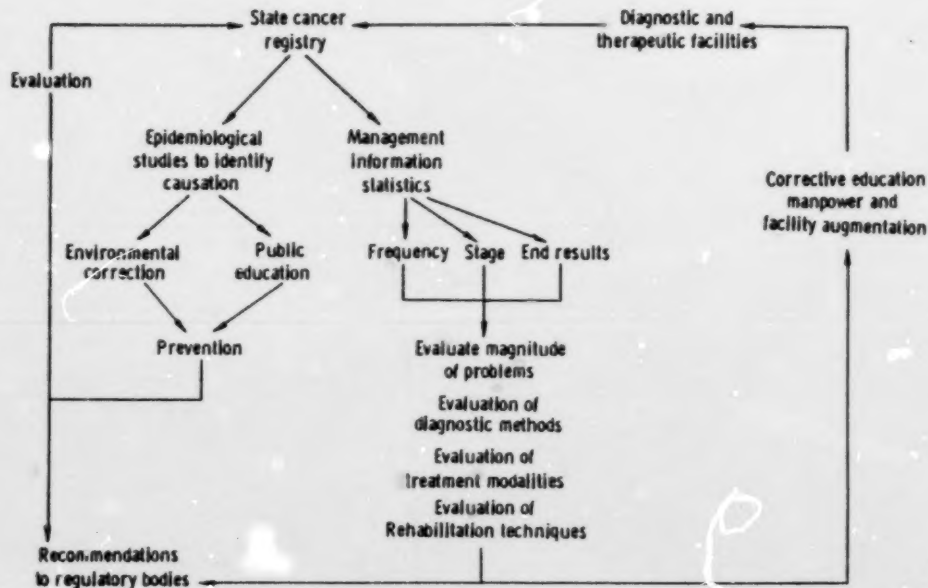
Perhaps one of the most complex areas of education is the education that goes on directly between the physician and the patient or the nurse and the patient attempting to motivate behavior that will permit the patient and his/her family to cope with extant disease and to insure optimum outcome and accelerated rehabilitation.⁴ If this proposition is accepted

FIGURE 1

FLOW DIAGRAM FOR A CANCER MANAGEMENT INFORMATION CENTER AT
THE CANCER RESEARCH CENTER IN COLLABORATION WITH THE STATE
CENTER FOR HEALTH STATISTICS

This diagram indicates how statistical feedback is used and evaluated throughout the state. The state cancer registry receives and disseminates information.

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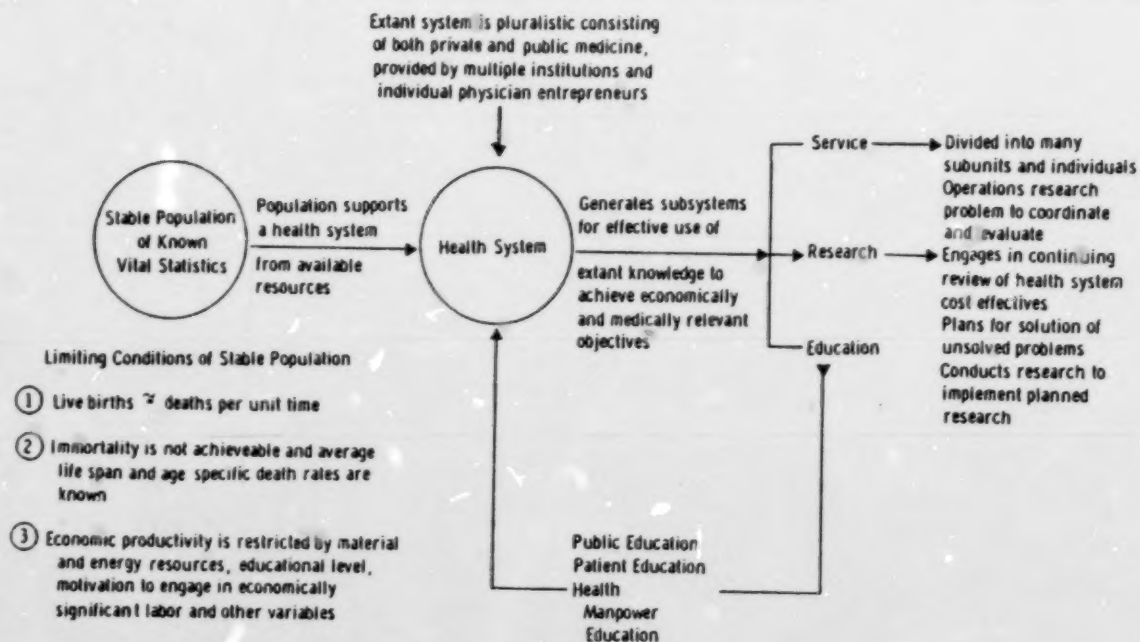


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FIGURE 2

RELATION OF THE HEALTH SYSTEM TO THE SUPPORTING POPULATION



The relation of the health system to the supporting population is a source of informational feedback from an epidemiological statistical unit such as Missouri's can-

cer registry to a cancer control program.

Reprinted from Spratt, J. S., Jr., Monaco, R. M., Hahn, R. C. and Cary, C.: Systems Analysis, Systems Management and Surgical Technology. J. Surg. Res. 18:844, Fig. 1, 1974.

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Original Source: "Cybernetics of Cancer Control by Prevention", Missouri Medicine, pps. 213-217, May, 1977.

rehabilitation is of great economic significance, then this educational effort must be cost-effective. A mathematical¹ model for considering the cost-effectiveness of the clinical process and the educational clinical actions has previously been published.⁵⁻⁷

The concept of cost effectiveness is not popular within the health care system since it has traditionally been held that no measure should be spared to insure patient outcome, and the patient outcome has precedence over any consideration of cost. Unfortunately, the actual conditions of society do not support this position without exceptions and many flaws in this concept can be demonstrated in actual practice. Furthermore, the imperfections of the health care system are such that the law of diminishing returns is operative as greater and greater expenditures will not necessarily be associated with better and better results. In fact, scenarios can be conceived in which additional expenditures would actually be associated with deteriorating results exactly as the law of diminishing marginal returns predicts.^{6,8}

Though the importance of this educational effort is well recognized, the health professions as a group have not been as active as should have been the case in either the evolution or adaptation of scientific educational methods to enhance the most cost-effective patient compliance. The degree of effectiveness of health education can no longer be ignored, due to the inflating cost of medical care. To do this, the "frontline educator" who is in actual patient contact needs a model such

as we propose in order to plan and evaluate the cost-effectiveness of his/her own effort.

Education for Patients

Patient education is as old as the doctor-patient relationship. Instructions on a one-to-one basis have always been given simultaneously with medical treatment. What is new about this concept is the innovative ways in which patients are now being educated.⁴ Due in part to increasing demands on physicians' time accompanied by increased numbers of non-physician health workers, the responsibilities and mechanisms for educating patients have evolved dramatically.

The Joint Committee on Health Education Terminology has defined patient education as

"those health experiences designed to influence learning which occurs as a person receives preventive, diagnostic, therapeutic and/or rehabilitative services, including experiences which arise from coping with symptoms; referrals to sources of information, prevention, diagnosis, and care; and contacts with health institutions, health personnel, family, and other patients."⁹

Ulrich and Kelly state that,

"Patient education should consist of organized health educational experiences, planned by physicians, professional health workers, and the patient himself to meet the patient's specific learning needs, interests, and capabilities, and offered as an integral part of the patient's total health care.¹⁰ (Emphasis added.)

Patient education must be planned activity by providers of medical care focused on the support of the patient to minimize

the patient's dependence on others in the recovery process. To achieve this goal, the patient must receive factual information about his/her condition, treatment, and prognosis. Moreover, education entails assessing other needs the patient may have, and most importantly, any information transmitted must be done in such a manner that the patient can interpret and integrate it within his/her own perspective to bring about attitudinal or behavioral changes beneficial to the person's future health status. In short, scientific facts must be couched in language the patient can understand to maximize the impact desired.

Patient educators need to remember the principles of learning theory in both the creation and presentation of educational materials. Effective patient education should incorporate information about what any patient "ought to know" with what the patient thinks he/she needs to know. In the case of cancer, one must determine those aspects of cancer and its management which are of primary concern to the patient. This will vary as greatly as do the patients themselves. The wealth of literature which exists on patient compliance underscores the fact that traditional (i.e., "what patient ought to know") instructional approaches have not resulted in improved patient compliance.^{11,12}

The dominant characteristic of patient education, whether formal or informal, should be its contribution to an individual's ability to manage his/her life with judicious, relevant, and parsimonious use of social support resources. Thus patients'

perspectives for health needs may differ vastly from professionals' perspectives. The serious consequences to the patient of incompatible definitions and goals in the doctor-patient relationship are well-known.¹³ The same holds true of educational goals if the patient and professional are not of like mind.

Cogswell and Weir have divided the educational tasks into four components -- teaching medical procedures, teaching medical explanation of physical condition, teaching reason for each medical procedure, and teaching simple diagnosis.¹⁴ Additional educational objectives would involve the many phases through which the patient moves from initial medical care contact to discharge status. For example, an educational program for a hospitalized cancer patient would include explanation of hospital policies, anxiety reduction program, discussion of normal and abnormal side-effects of treatment regimens, nutritional needs, exercise and post-discharge routine, etc. Such a program aids the patient's physical recovery as well as assists the patient to become confident in exercising responsibility for his/her own care.

Modalities of education vary considerably. Pamphlets, booklets, charts, posters, recordings and various audio-visual techniques supplement one-on-one instruction. Pamphlets predominate in patient education and are questionable as to their effectiveness.⁴ St. Anthony's Medical Center in St. Louis has implemented a host of educational films which patients can select via closed-circuit television. A more

recent method for patient education is the team approach. The involvement of many health providers in assessing patient's needs, capabilities, concerns, social conditions, and resources will facilitate the total educational effort; furthermore, if this team is well orchestrated it will improve the patient's total understanding of his situation, and foster the patient's ability to actively engage in managing the health condition.^{4,11}

Patients are audiences for education in physicians' offices, waiting rooms, classrooms, hospital beds, outpatient centers, as well as at home. Undoubtedly, the objective of the education will dictate who teaches, where it is taught, and what modality will be utilized. Informing the patient of the events, procedures, and happenings will minimize the distorted images patients must contend with as they cope with cancer. We'll return to this point when our conceptual framework is presented.

Voluntary and professional organization, commercial firms, and medical staffs produce the majority of education materials. Information to meet specific patients' needs, or aligned with specific therapeutic regimens inherent to a particular medical setting, is probably best created by staff persons in that setting as information accumulated through their clinical experiences may not be relevant elsewhere. It is critical, however, that educational materials be consistent with verbal instruction to gain patient compliance.

The development of patient education programs for institutions to systematically implement which go beyond specific illnesses are a recent phenomenon and have grown in the 1970's. A 1975 survey of almost 4700 hospitals regarding their inpatient

education programs revealed the following.¹⁵ Fifty-seven percent had at least one inpatient program. However, only one out of every eight hospitals had an overall patient education policy. Committee structures were used in 17% of the hospitals to generate and monitor patient education, and these committees were dominated by nurses and physicians. By way of assessing the impact of patient education (i.e., evaluation) the vast majority cited observations of task performance as the technique. Statistical comparisons of readmission rates and inpatient education referrals were the least used methods of evaluation (9.3% and 5.8%, respectively).¹⁵

Due to the developing nature of patient education, many simple questions remain unanswered. The most significant question raised concerns the effects of new knowledge on patient behavior. Some programs have taken steps to scientifically assess these effects and are noteworthy for their pioneering efforts.¹⁶⁻²² The majority remain unevaluated.

Theoretically, the benefits of patient education programs include boosting staff morale, increasing the awareness of patients' total needs, new and innovative ways of delivery services, standardization of many health procedures, professional cooperation, and an integration of inpatient, outpatient, and community follow-up techniques. All presumably will foster better patient care in a cost-efficient manner.^{4,23} Such benefits are offset with realistic problems: implementation, variability in organizational size; staff training, development and preparation; record keeping for feedback, accountability

and monitoring; time constraints on patient-professional interaction; spiralling cost of medical care, etc. It is patently obvious that the health care system seeks to maximize the benefits and minimize the inherent difficulties. One author suggests that systematic "patient" education of children will minimize the barriers they perceive as adults and consequently enhance compliance.²⁴ However, in order to begin to make such determinations we need first to develop a system for assessing the impact of patient education.

An Overview of Evaluation Research*

We have witnessed a widespread use of health education with inadequate provisions for adequately testing the effects of such education.²⁵ State and federal legislation concerning social service programs since the late 1960's has increasingly included evaluation mandates in the text. The reasons for this government interest in scrutinizing social programs for their effects are disillusionment with social institutions, increasing level of skill attainment in measurement by social scientists, growing interest in social engineering, social indicators development, and political to name a few.²⁶⁻²⁹

*Space and time limitations permit only a summary. General texts should be consulted for more indepth reading. E.A. Suchman's Evaluative Research: Principles and Practice in Public Service & Social Action Programs or C.H. Weiss's Evaluation Research: Methods of Assessing Program Effectiveness are highly recommended.

What is evaluation research and what can it do for patient education approaches? Addressing this latter point first, evaluation can provide evidence that will reduce the uncertainties or at a minimum clarify the gains in patient outcome that are attributable to the educational endeavor. Weiss maintains that evaluation is a type of research that "measures the effects of a program against the goals it set out to accomplish as a means of contributing to subsequent decision making about the program."²⁹ Suchman makes a distinction between evaluation ("social process of making judgments of worth") and evaluation research ("utilization of scientific research methods ... for the purpose of making an evaluation").²⁸ Angrist regards evaluation research to mean "research whose task is to assess a situation or program and to provide information for decision making."²⁶ From the above definitions and others, two central points are clear about evaluation research; a) assessment of impact is determined by the scientific process, and b) the outcome of this endeavor is the basis for decision making.

Too frequently it is erroneously thought that only upper management personnel are the sponsors and benefactors of evaluation research results. However, personnel at many levels in an organization can sponsor and derive benefits from such research. For example, a hospital administrator's decision may be whether to expand an educational program hospital-wide, whereas the chief of surgery may be more concerned with the staff patterns in pre-operative counseling aimed at reducing patient anxiety.

A significant dilemma permeates the current practice of evaluation research. It is rare that the decision maker is faced with the dichotomous question of continuing or discontinuing a program. Usually he seeks information allowing him evidence to alter or refine a program to better achieve the program's original purpose. The question may involve budget allocations, or theoretical assumptions underlying the program, or to assess if the program is moving (and how fast) in the desired direction, or to gain support from interest groups, or for promotion, etc. Questions for evaluation research are derived from two primary perspectives, individual decision makers or the organization at large, and often have hidden reasons or motivating factors.²⁸⁻³⁰ Unfortunately, the setting for evaluation is always encased in action and our design methodology for assessments in such environments is relatively underdeveloped for decisions other than the uncommon continue/discontinue.^{26,28-33}

Evaluation research often is considered to be applied research rather than basic research. This has consequences for sampling, variable control, and measuring the effect criteria.^{28,29} One can never be assured that the "effect" desired is the result of the "cause" due to the action setting in which such research is conducted. For these reasons as well as others, the vast majority of results stemming from evaluation research are less than meaningful. Frequently no effects are found because the wrong variables are being measured, the desired

factors have no quantifiable indicator, or extraneous variables function to wash out associations.³⁴ DeVall concludes that "the specialization of functions within one and the same change process is hardly beneficial for the impact ... and constitutes one of the reasons why that impact is generally found to be wanting."³¹

Other problems associated with evaluation research particularly in the area of patient education have to do with representativeness of the population selected for study,³³ cost factors,³⁵ selection of priorities, professional-practitioner role conflicts,²⁹ time frames for educating the patient, biased third parties,²⁸ serendipitous events, inflexible research design,^{29,36} and the "lack of any systematic analysis of the theoretical, methodological, and administrative principles" underlying the educational process.²⁸ With increasing attention to the methodology of evaluation significant inroads are being made in minimizing the above limitations. Research designs are becoming more flexible within action settings, yet remain cognizant of the validity and reliability issues. The absolute necessity of evaluation being a key part of program planning and implementing stages is one strategy certain to minimize these limitations and promote staff acceptance of the research.^{32,37,38} The quick feedback of information to recipients also will exhibit the utility of such research, encourage program refinements and foster staff-patient satisfactions with the program. An increasing ability to identify and measure key variables has evolved within the

behavioral sciences to provide quantitative evidence for decision making.³⁹

The purposes of evaluation research theoretically outweigh the above limitations. Initially, we stated that the primary purpose of evaluation is to provide evidence for rational decision making. Our concern is with determining the kinds of effects various educational strategies will have on patient outcome, and to assess the durability of such effects. Almost all authors in evaluation research provide classification schema for the key questions which evaluation research may address.^{26,28-32} Presented below are the issues one author suggests as the main uses of an evaluation study:⁴⁰

- "1. To discover whether and how well objectives are being fulfilled.
2. To determine the reasons for specific successes and failures.
3. To uncover the principles underlying a successful program.
4. To direct the course of experiments with techniques for increasing effectiveness.
5. To lay the basis for further research on the reasons for the relative success of alternative techniques.
6. To redefine the means to be used for attaining objectives, and even to redefine subgoals, in the light of research findings."

The method of answering such issues as they relate to patient education in an atmosphere of cost-effectiveness is of critical importance given the current direction of the health care system.

Toward A Conceptual Model For Evaluating Patient Education

The above discussion briefly outlines the purpose of evaluation research as well as providing some of the associated advantages and disadvantages. The emphasis in this section is upon the conceptual methodology of evaluation in order to achieve what is desired. Several models are reported in the literature to assist in this task.^{25,26,28-32,25,41-43}

Steps of Evaluation Research

The language of evaluation differs among the various authors. No matter the labels attached to the process, common elements stand out. First and foremost, the goals of the program need to be clearly stated in a manner which affords measurability. The goal or goals to be evaluated must be identified from among all the goals of the program. The assumptions or theories of the program must be made known. This would include such value laden statements like "educating the patient can only be beneficial in the long run." Some yardstick of success must be identified. A program ----> cause ----> effect relationship must be established. This may be in the form of hypotheses but is not required. The variables -- independent, intervening, and dependent -- must be identified. Indicators of these variables must be developed and units of analysis must be specified.

After the above steps are completed, one must have a research design for gathering data to provide the scientific answers to the issues raised. This is one of the most crucial phases because ultimately one must answer with confidence the implicit or explicit question: "Was the effect due to the program?" An

ill conceived design is equivalent to no research at all.

Campbell and Stanley have classified numerous research designs into three types -- pre-experimental, experimental, and quasi-experimental.⁴⁴ Pre-experimental designs are only for preliminary examination of effects. Done properly they are rich in insight, descriptive of detail, and inexpensive. Some of these designs do not require baseline measures, others ignore the need for comparative groups. Their utility is in the formative type of evaluation. The inherent weakness is evident, the effect can not be directly linked to the program "cause". It is only suggestive, that is, formative.

The essential difference between the experimental designs and quasi-experimental designs is the randomization of subjects. In action settings such as doctors' offices, clinics, and hospitals, it is almost impossible to randomize patients. These are dynamic environments and if too many variables are controlled the experiment most likely is not able to be generalized to the real world. Quasi-designs are more practical, have an inherent logic of their own, and should be chosen carefully depending upon the sacrifice to internal and external validity one is willing to risk.^{33,34} We cannot over-emphasize the importance of design in evaluation research.

Once the above stages are completed, the research is completed by data collection, data processing, data analysis, and reporting. The finished product should then be used in directing any decisions about the program. This final stage may or may not be dependent on the evaluation results as the decision making

process is as much judgmental as it is rational.^{28,29} One final note of caution, the entire research process assumes that resources are available for the necessary activities and that the practitioners are as committed to the study as the program managers are. Obviously this is not always true.

Objectives of Patient Education Evaluation

To be effective, patient education programs must have some explicit goal in mind before implementation. Generally, individual programs have multiple goals which may be interrelated horizontally, vertically or both. Such objectives could be immediate (reducing pre-biopsy fears of woman with lump in breast), intermediate (teaching arm exercises to mastectomy patient to reduce lymphedema potentiality) or ultimate (increased survival time for cancer patient). Evaluation of patient education programs must first begin assessing the impact of immediate objectives as they are the most practical. Ultimate objectives are the most difficult to evaluate due to the latency period of disease and the wide host of intervening events of which the researcher has little awareness. The immediate and intermediate objectives are the most crucial for patient education given the time constraints and the techniques available.

The objectives should be arranged in a descending order, beginning with the ultimate (reduce mortality) and ending with the administrative actions necessary to implement patient education. However, when one begins to evaluate, the initial

efforts must be at the lower end of this continuum and work towards intermediate and ultimate objectives. Each initial sub-objective must precede the next intervening sub-objective and so on until the ultimate objective is evaluated.

It was noted earlier that the underlying assumptions must be made known for each objective. Validity assumptions being associated with objectives therefore should be listed in descending order. Suchman has stated:²⁸

"Hence, every lower-level objective must assume all the assumptions made for all the objectives above it Any program which is based on a fake set of major assumptions cannot be rescued by its lower-level objectives."

For example, sound evaluations can be made of ways to motivate patients to adhere to diets, even though the dietary materials are completely false. Some assumptions are proven through prior research, but others must be assumed to be valid. In the latter case, we must proceed with caution because at whatever level an assumption is shown to be wrong, all activities below it are in error as well. Also it should be noted that the higher the level of the patient education objective and assumption, the more generalizable the findings.

In sum, objectives and their assumption of validity move from high-level to low-level, but the activities of assessing impact move in the opposite direction.

Criteria For Patient Education Evaluation

The determination of whether or not a patient education strategy is successful or not is dependent upon the criteria

employed to make such an assessment. In the broadest framework, the distinction can be made between the "efforts" of the strategy versus the "effects" of the strategy. The criteria differ depending upon who you read. DeVall proposed four models based upon criteria of feedback, change, control and role sets.³¹ Longest suggests the use of context, input, process, and product criteria.⁴² Deniston and associates are concerned with the process of achieving sub-objectives in a specific order as the criterion.⁴¹

Patient education evaluation best lends itself to the criteria proposed by Suchman.²⁸ Briefly these are effort, performance, adequacy, efficiency and process. Because so little is known about the various patient education strategies much can be gleaned by asking rather simple questions and developing the appropriate measurements and designs to seek their answers.

Assessing the activities involved in planning and implementing an educational strategy such as in-hospital group counseling can be determined regardless of the output variables (effort). Determining the proportion of laryngectomy patients who remain free of upper respiratory infections six months after participating in an inhalation therapy program measures the results of effort rather than the effort itself (performance). Patients often have needs beyond their cancer condition. An educational program designed to assess the totality of these needs and then tailored to meet them would be a measure of adequacy. Such a measure is always relative, but for a cancer patient, it must include needs of four specific time frames -- pre-operative,

immediate post-operative, convalescent, and post-discharge.

Efficiency criteria are most often used in attempting to compare the input/output ratio of one particular educational strategy with that of another. For example, all female patients (regardless of the setting) may be instructed about the advantages and techniques of breast self examination. An efficiency assessment would be to determine whether or not nurse demonstrations are more effective than pamphlets without demonstrations. The final criterion, process, is not evaluation research in the strictest sense of that term, but is concerned with making sense out of the overall educational endeavors. This would include such factors as the population exposed to the education, specification of program attributes, clarification of program conditions, and the type of effects (cognitive, attitudinal, or behavioral).²⁸

System Approach to Patient Education Evaluation

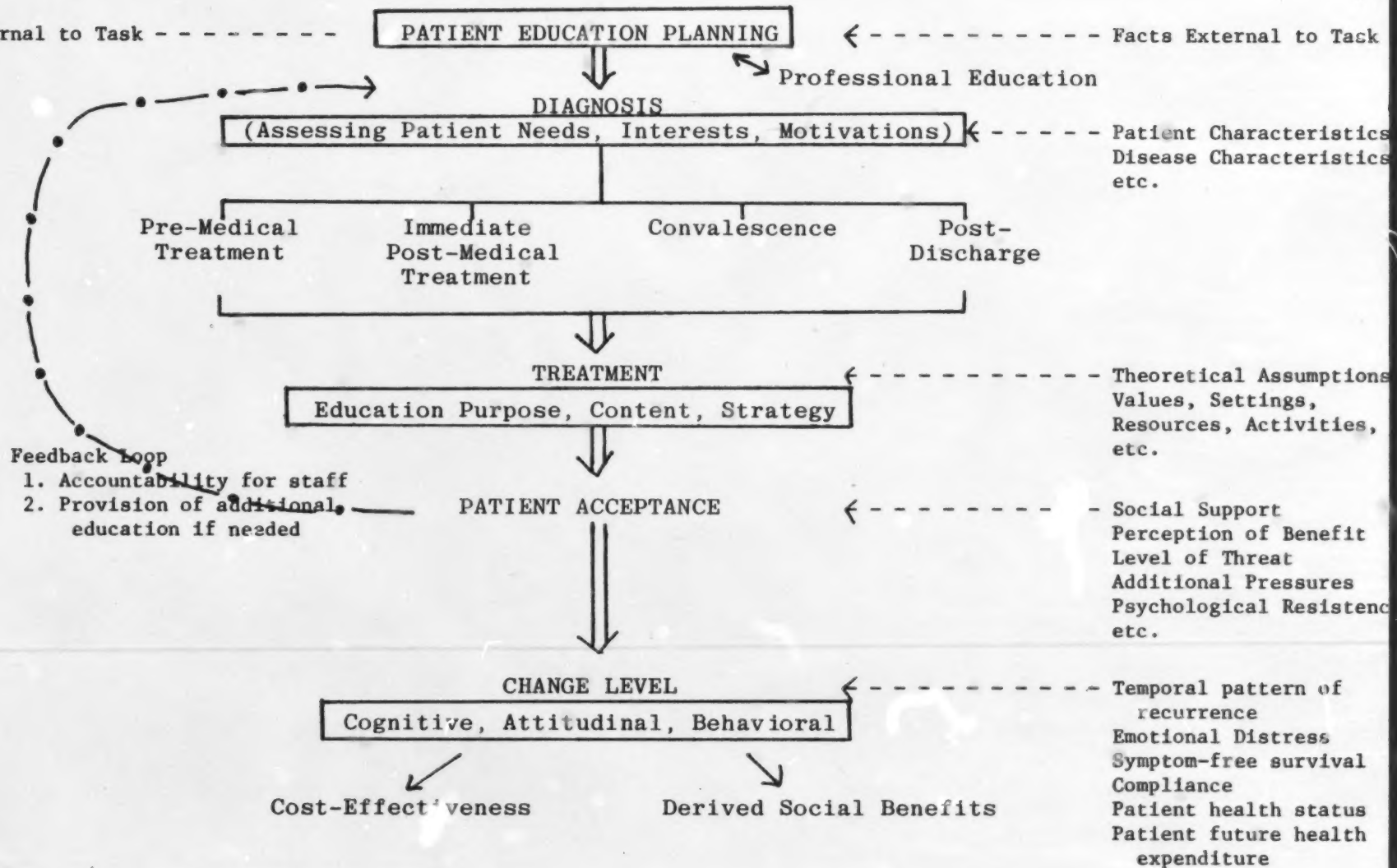
The key to the success of patient education is to get the right information to the right place at the right time to the right person in the most economical way possible. The doctor-patient management of a disease can be augmented by their peers. This includes non-physician health personnel and the patient's family. In short, the reservoir of educators is significantly magnified. A systems perspective of patient education is provided elsewhere and is not the focus of this paper.³

A systems design for evaluating any educational strategy will help clarify the cause-effect association and provide for the accountability for each of the involved parties. A

diagram of this model is presented in figure 3. Examples of input, intervening, and output variables are provided. Of course, selection of such variables is dependent on many factors like the goal statement, the motive for the evaluation, availability of resources, and the overall priority of the project.

FIGURE 3

SYSTEMS APPROACH TO PATIENT EDUCATION EVALUATION



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